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ABSTRACT

One clinical psychologist who worked with terminally ill, end-stage Acquired Immune Deficiency Syndrome (AIDS) patients in a hospice type setting experienced more than 150 deaths over an 18-month time period. Many of the patients denied that they had AIDS; some distinguished between having AIDS and testing positive for Human Immunodeficiency Virus (HIV+). For many of the patients, having AIDS was emotionally shattering, personally devastating, and overwhelmingly terrifying. This paper describes the experience of working with a clientele of AIDS patients. Case examples and quotes from a variety of these patients illustrate the feelings experienced by persons with AIDS and, in some cases, reveal the psychological mechanisms used by AIDS patients to deal with their own mortality and the death of other patients. Freudian, fundamentalist, and sociological interpretations of AIDS are discussed briefly. It is concluded that in certain ways, humans contribute to their dysfunctional immunological systems: by taking an active role and responsibility in their treatment, changing their thoughts about death and dying, maintaining a positive attitude, using meaningful spiritual values, confronting boredom, and finding more meaning for existence, some AIDS patients may be able to extend their lives and arrest their conditions. Psychological interventions are discussed as important for those diagnosed as HIV+ and for those with AIDS as well as for persons who care for them. (NB)

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"The Creative Use Of Psychotherapy With Terminally Ill Aids Patients"

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This paper presents information on the work of a clinical psychologist working with terminally ill, end-stage, Aids patients in a hospice type setting located in northern New Jersey where he experienced more than 150 deaths over an 18 month time period. He will highlight some of his current experiences and share his perceptions on what psychological mechanisms such patients appeared to be using to deal with their own mortality and the death of other patients. He will conclude with his views and recommendations on the importance of psychological interventions for those diagnosed as HIV+ and those with Aids as well as those who care for them be they staff, family, friends, lovers or significant others.

I never really fully knew or understood what having Aids must have meant to any of the patients I worked with these past 18 months. Yes, I began to know something about their psychological make-up, but not very much about their personal response to Aids. All of the patients had already been informed, or we presumed they knew they were infected. Several bitterly denied they had Aids. For some, it was more acceptable if they said, "I really don't have Aids. I am HIV+." I never really knew what their original responses, feelings or reactions were at the time they either discovered it, suspected it, or were actually told, "You have Aids." I came after the fact, after the telling or knowing.

I listened to some of their feelings and upsets. I offered some of them solace, encouragement, hope, or reassurance, and assuaged others of their guilty feelings. I tried to explain some of their behaviors, dreams and nightmares. I indicated why I thought they might be apprehensive, angry, frightened, depressed, sad or suicidal or why they appeared to be denying their illness, or thought they would be better off dead or wanted to kill themselves or wanted to give up on life; but I never knew what they must have felt, experienced, feared or knew when they were informed or believed that they had Aids.

I tried to identify with each person. I empathized with them and tried to imagine what it must have been like, felt or meant to them, to no avail.I failed each and every time. I just never knew. In some ways I thought it was similiar to experiencing combat in times of war.Yet even in such times,combat war experiences seemed to always be very personal. My feelings about combat and war differ widely from those of other combat vets. I wound up believing that each human being has to come to terms with his/her own mortality. Each of us has to face our lives and our deaths individually. We seem to experience both life and death differently from one another. It was this conclusion that lead me to ask some of the patients what Aids meant to them. In those instances where this was not possible to do, I relied on my clinical skills, observations and understandings of each patient and his/her unique set of psychological issues, concerns, or problems presented. This gave me a clear-

er understanding as to what dying and death seemed to mean for each person. I know I didn't have all of the right conclusions; but I also know, having lived through such a large number of these deaths, that I did have a few thoughts on the matter that were probably very accurate. I came to understand that for many of the patients, having Aids was emotionally shattering, personally devasting and overwhelmingly terrifying. Can you imagine being told that you have Aids? What would you say? What would you feel? How would you respond if you were told, "You have Aids and should not expect to live more than a few years?"

A 39 year old white, bisexual male once told me..."You know Doc, I was having a great life, not a care in the world, had all of the material possessions I could ever want; big bucks in my pocket, travelled the world, fancy house, two sons, great car, women, men, friends, rings on my fingers, wore $750.00 suits. I had absolutely nothing anymore when they told me in the hospital that I had Aids. It jolted me, stopped me in my tracks...my life, my high-living life was over...I knew if I was to live, to survive, that I had to change what I was doing...but do you know something Doc? I couldn't change. I went crazy...I shot up my arms so much it was all punctured like a sieve...I gambled away all of my money and everything I owned...I destroyed my body with drugs and booze... I almost didn't make it...now I'm still dying, but at a much slower pace, and not enjoying it one bit. Iknow I have terminal Aids and will die in a few months."

Another patient, a 28 year old single, Hispanic male said to me one time, "Life's no longer a joke any more...I got to take things more serious now."
A 73 year old jewish woman exclaimed, "It's unfair, why me? Why me?."
A very dignified elderly black man of 62 years of age, married with three daughters and one son, kept saying over and over again, "Has to be some mistake, Doc...has to be some mistake."

I suppose some Freudian analysts or psychoanalysts might say that Aids is the consummation of the "Death Wish" and is a consequence of a a former life filled with many personal inadequacies and personal emotional deficits that lead to either the individual running away from home early in life or perhaps the person had been abused in some way or dropped out of school early or had some brushes with the law or shot up with drugs or screwed around sexually or shared dirty needles. Aids, in such cases might be for some a way of atoning for guilt at being such a miserable, life failure.

Some politically vocal conservative Fundamentalists proclaim that Aids is God's way of punishing and removing from this earth all of the scum or refuse from our modern day Sodoms and Gomorrahs, notably the homosexuals and drug abusers. Were we to follow their bigoted line of thinking we would all be damned to eternal hell as we see increased evidence of Aids in babies, adolescents, lesbians, bisexuals and heterosexuals. Who would be exempt? Would all of us be punished and removed?

Some sociologists might think that Aids represents a world gone mad, a loosening of moral values, the breaking up of the family structure, hedonism run amuck, and people obsessed with the 'good life'; a world of disillusionment, decay and the fall of western civilization, as well as the eroding of democratic institutions.

My understanding and experience with persons with HIV+ and Aids leads me to conclude that in certain ways, humans contribute to their dysfunctional immunological systems. I also strongly believe that some terminally ill Aids patients can extend their lives and some can arrest their condition. I see this done when such persons take a more active role and responsibility in the treatment process, change their thoughts about death and dying, maintain a positive attitude, utilize meaningful spiritual values, confront their boredom and begin to find more meaning for their existence. Yes, I affirm the seminal work of Viktor Frankl and his Logotherapy in the psychological treatment of this condition. I also see unusual opportunities for those psychologists who may be bored or are seeking more meaningful work by applying their expertise to this field of endeavor. We psychologists have many contributions to make leading to a better understanding of the onset of HIV+ and Aids as well as in areas of care and treatment. We have the opportunity to take a leadership role in prevention, education, training, diagnosis, treatment, after-care and research.